Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research – Questions on draft Statement

Following consultations in 2024 that sought views and opinions on how the Statement could be improved, NHMRC and the Consumers Health Forum of Australia (CHF) have released a draft revised Statement.

Revising the Statement provides an opportunity to streamline and refocus the content to help to shape consumer and community involvement policy at all levels into the future. It emphasises the principles and values of consumer and community involvement and the roles and responsibilities of all involved in health and medical research.

You may enter your responses directly using the online survey. If you provide an email address, you can save your progress and return to the survey as many times as you wish while it is open.

This document has been developed for individuals and organisations who would prefer to prepare their responses offline, for entering on NHMRC's Consultation Hub once complete. It contains the discussion questions in the order that they appear in the online survey.

Please note that none of the questions below are mandatory, and that there is no word or character limit for each question in the online survey. You are welcome to provide a response to as many or as few questions as you wish. You will also be asked some questions about you or your organisation when you complete the online survey.

Please ensure that you have read the Statement (available for download on the 'Overview' page of the survey or from NHMRC's website) prior to answering the questions.

Expectation of Consumer and Community Involvement in health and medical research

While the Statement does not mandate consumer and community involvement, it sets high expectations. The goal is for consumer and community involvement to become a routine and integral part of every level, stage and type of health and medical research.

- Does the Statement set clear and suitable expectations that consumers and community will be involved in all stages of research?

Yes ☒
No ☐

Would you like to make further comments?

The National Rural Health Alliance (the Alliance) thanks the National Health and Medical Research Council (NHMRC) and Consumers Health Forum of Australia (CHF) for the opportunity to comment on the draft Statement on Consumer and Community involvement in Health and Medical Research.

The draft Statement is measured and holistic in its approach to community involvement in health and medical research. The Alliance sees an opportunity to strengthen the language of the statement and shift to an action-driven tone that focuses on the implementation of the concepts introduced in the Statement. In its current iteration, the Statement, while goal orientated, reads more as a guidance than an active Statement of requirements.

Although it is not the purpose of the Statement to mandate community involvement, it is important that the language provides a directive, action-orientated tone to ensure that researchers, research organisations, funders, and community members view this as a high standard expectation in providing quality research outcomes. This is of particular importance in rural and remote health research, as communities are a strong source of knowledge in what healthcare interventions are required in their communities and are often engaged in providing innovative co-designed solutions to meet these needs in areas of limited resourcing.

Despite representing approximately one third, or over 7.3 million people, of Australia's population, rural Australians face poorer health outcomes due to geographic isolation, limited infrastructure, and ongoing health workforce recruitment and retention issues. A lack of rurally focused and community-based research perpetuates these poorer outcomes. An analysis of NHMRC funding data from 2015 to 2025 found that grants explicitly focused on improving rural health outcomes in Australia accounted for just 1.75% of total grants awarded. In no single year during this period did rural-focused grants exceed 3.45% of total grants.[1] This is particularly disappointing considering that 2/3rds of Australia's export income, 50% of tourism income and 90% of food comes from rural Australia i.e. it contributes considerable wealth to the whole Australian population.

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[1] Data was sourced from the NHMRC *Outcomes of Funding Rounds* page. Grants were counted if they explicitly referenced "Rural and Remote" or "regional" in the context of Australian geography. Mentions of rural, remote, or regional in international or unrelated clinical contexts were excluded. Grants lacking sufficient description or relevant keywords were also excluded. Data was compiled from the raw data tabs of downloadable tables and manually reviewed for inclusion.

These unique barriers to healthcare access and research equity also means that applying metropolitan centric healthcare policies and research concepts to issues faced by rural communities are often not fit for purpose. Moreover, even with the same research methods that work for one rural community often does not yield the same results as another community. This is because cultural, social and healthcare needs in each community have their own unique context.[2] Therefore, community and consumer involvement in rural health research is imperative to cultivating meaningful outcomes and creating supportive, person-centred models of care for an at-risk population. For health service deliver to and research to be impactful, we must place it in context.

The rural context demonstrates that the exclusion of communities and consumers from health research compromises the quality, relevance, and overall impact health of research. Indeed, ultimately, health outcomes. Establishing a clear, authoritative statement that compels researchers, funders and institutions to meaningfully and equitably engage communities and consumers is essential to improving health outcomes and ensuring equity in research processes and results. Poorer health access and health outcomes, as well as much earlier deaths in rural communities are a clear message, that there is more to be done to reach parity and equity in Australia.

Values and Principles of Consumer and Community Involvement

The Statement outlines the values and principles that are the foundation for effective consumer and community involvement.

- Does the Statement clearly explain the key values and principles that ensure effective consumer and community involvement?

  Yes ☒
  No ☐

  Would you like to make further comments?

The Alliance supports the Values and Principles outlined in the draft Statement.

The Values outlined in the draft Statement set clear expectations and professional boundaries that are integral to creating high-quality research outcomes for both the researchers, consumers and community participating in health research. The Alliance notes that there is provision to add ‘self-determination’ as a value in consumer and community involved research. This is of particular importance in context of data sharing when collaborating with Aboriginal and Torres Strait Islander communities.[3] Having ownership within a research project is important for community involvement

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[2] Mathias, H., Duff, E., Schulz, P., Auger, S., Gravel-Ouellette, A., Lockhart, T., McCorriston, W., McCrindle, J., Mirza, N., Pijl, E., Savard, T., & Hyshka, E. (2025). Rural community-based participatory research with families of people who use drugs: key considerations from a multi-provincial research partnership. *Harm Reduction Journal*, *22*(1). https://doi.org/10.1186/s12954-025-01247-3

[3] Snijder, M., Wagemakers, A., Calabria, B., Byrne, B., O’Neill, J., Bamblett, R., Munro, A., & Shakeshaft, A. (2020). “We walked side by side through the whole thing”: A mixed-methods study of key elements of community-based participatory research partnerships between rural Aboriginal communities and researchers. *Australian Journal of Rural Health*, *28*(4), 338–350. https://doi.org/10.1111/ajr.12655

and is an important component of Aboriginal and Torres Strait Islander health research.[4] This addition would also ensure that the Values align with data governance and sovereignty principles, ensuring research has a meaningful and culturally appropriate impact on the health outcomes of Aboriginal and Torres Strait Islander people.[5]

The Alliance believes that the Principles of consumer and community involvement in health and medical research adequately reflects the needs of rural participants in consumer and community involved research. The Statement adequately communicates the involvement of community and consumer partners in research must be across the lifespan of the research project and beyond. It is crucial that there is a commitment to increasing health, health research and health system literacy as part of the process of being involved in research, where those involved have the opportunity to learn about the process and outcomes of the research on their communities or greater society.

The Alliance is particularly pleased with the inclusion of the statement "Consumers and communities must be provided with appropriate training, support, and remuneration so they can be involved equitably" under *Principle 4: Equitable inclusion of diverse consumers and communities.* Indeed, those on grant review panels should also have equal voting rights, as their expertise may not be research, but it is based on situation and experience.

Capacity building and support are of great importance in rural health research for communities where research opportunities have been limited and capacity is diminished due to strained resources. The opportunities for rural research therefore must be context specific and focused on building research as well as health literacy capacity. Research should be focussed on providing positive outcomes in these communities while also avoiding adding additional pressures on a limited health workforce and human resources which may result in burnout.[6]

Similarly, the inclusion of *Principle 6: Safety of consumers and communities* is very important for rural health research. Many community research participants engage in projects to provide better health outcomes for their communities and are more likely to be involved as opposed to urban people, due to a culture of community involvement. In rural Australia, this also means that people undertaking these activities often do so in addition to family and/or caregiving responsibilities and work responsibilities in a voluntary capacity. In small communities such as those in rural and remote Australia, this can also often mean that consumer and community research partners have strong involvement and often lived experience with the health issues and barriers they face, that researchers may be investigating.

Existing research on the involvement of rural consumers and community research partners noted that this can be a challenge for rural consumers and there can often be issues for research teams to find accessible support services to assist for community and consumer partners due to limited health

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[4] Snijder, M., Wagemakers, A., Calabria, B., Byrne, B., O'Neill, J., Bamblett, R., Munro, A., & Shakeshaft, A. (2020). "We walked side by side through the whole thing": A mixed-methods study of key elements of community-based participatory research partnerships between rural Aboriginal communities and researchers. *Australian Journal of Rural Health*, *28*(4), 338–350. https://doi.org/10.1111/ajr.12655

[5] *Data sovereignty - Cultural Ways*. (n.d.). Australian Indigenous HealthInfoNet. https://healthinfonet.ecu.edu.au/learn/cultural-ways/data-sovereignty/

[6] Alston, L., Field, M., Buccheri, A., Brew, F., George, A., Wheaton, N., Harrington, S., Payne, W., Aras, D., Bennett, A., Beks, H., Namara, K. M., & Versace, V. L. (2025). Establishment of a Research Unit in Colac, a Medium Rural Town: An Update on Progress and Guidance for Rural Health Service Research Strategy Development. *Australian Journal of Rural Health*, *33*(1). https://doi.org/10.1111/ajr.70005

services.[7] Budgeting and funding must also take into account extra costs that may be incurred in providing rurally-based community and consumer research partners adequate support that may be required throughout their participation in the project i.e. time, travel, accommodation if needed. It is therefore important that research partnerships are flexible to the needs of consumer and community partners. This may involve allowing participants to focus their participation on activities that match their interest, expertise and capacity.

Roles and Responsibilities for Consumer and Community Involvement

Many of the roles and responsibilities are shared between consumers, communities, consumer organisations, researchers, institutions, and funders, with different individuals and groups responsible for different aspects. Table 1 of the Statement outlines how these responsibilities can be shared.

- Does the Statement clearly explain the **shared roles and responsibilities** of all involved to ensure effective consumer and community involvement?

Yes ☒
No ☐

Would you like to make further comments?

The Alliance agrees in principle with the Roles and Responsibilities outlined in Table 1. Under the role of Research governance, the Alliance notes that there is provision for updating the statement to: "*Institutions and funders are responsible for providing consumers and communities with a balanced voice in research governance, such as ensuring consumer and community representation on boards and advisory committees*." The addition of "balance" is important to mitigate the unintended consequence of creating a power imbalance in research advisory committees and Boards. For example, if there is only one community representative on a Board of research professionals, there is a potential for a power imbalance to inhibit information sharing from a consumer and community representative. Having a second consumer or community representative may assist in addressing this imbalance and creating a support system for community representatives to feel safe and heard in a potentially unfamiliar setting. In addition, consumers/community members bring their own expertise, just as researchers do, hence should be seen as an integral aspect of development and change long after the researchers have moved on to another research topic.

The Alliance is pleased with the inclusion of the statement: *"Institutions and funders ensure adequate resourcing and funding for effective consumer and community involvement"* under the role of Resourcing, networking and recruitment. Funders should allow for additional financial support to appropriately engage rural communities in research partnerships. Due to the tyranny of distance, rural communities often pay a higher price for goods and services. This can often be a barrier to conducting research in rural areas and may lead to researchers not having adequate funding to engage rural community and consumer involvement. There is a

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[7] Mathias, H., Duff, E., Schulz, P., Auger, S., Gravel-Ouellette, A., Lockhart, T., McCorriston, W., McCrindle, J., Mirza, N., Pijl, E., Savard, T., & Hyshka, E. (2025). Rural community-based participatory research with families of people who use drugs: key considerations from a multi-provincial research partnership. *Harm Reduction Journal*, *22*(1). https://doi.org/10.1186/s12954-025-01247-3

serious potential unintended consequence of researchers avoiding participating in rural research due to funding limitations, leading to inhibited research outcomes, worse policy or the development of strategies that do not reflect a feasible pathway for implementation for rural and remote Australians. Funders must allow for higher goods and service costs in research and funding budgets to mitigate this risk.

- Does the Statement clearly explain the roles and responsibilities of **consumers, communities, and consumer organisations** that ensure effective consumer and community involvement?

  Yes ☒
  No ☐

  Would you like to make further comments?

  The Alliance agrees in principle with the Statement's explanation of the roles and responsibilities of consumers, communities, and consumer organisations that ensure effective consumer and community involvement. It believes that research funding should have parity and equity for rural Australians compared to urban research expenditure. The equitable inclusion of rural Australians in research would provide an insight into the 30% of the population's health and well-being, as well as solutions from the ground up.

- Does the Statement clearly explain the roles and responsibilities of **Researchers** that ensure effective consumer and community involvement?

  Yes ☒
  No ☐

  Would you like to make further comments?

  The Alliance agrees in principle with the Statement's explanation of the roles and responsibilities of Researchers that ensure effective consumer and community involvement.

- Does the Statement clearly explain the roles and responsibilities of **Research Institutions** that ensure effective consumer and community involvement?

  Yes ☒
  No ☐

  Would you like to make further comments?

  The Alliance agrees in principle with outlined roles and responsibilities of Research Institutions to ensure effective consumer and community engagement. Under the responsibility of "Creating a safe environment by assisting researchers to accommodate the needs of individual consumers and community members", the Alliance proposes that this is elaborated upon further.

  It is the responsibility of research institutions to also build capacity within the rural research workforce, their peers, to appropriately engage in trauma-informed, culturally safe, co-design practices. This goes beyond assisting researchers in making accommodations for consumer engagement. At the core, this must be a commitment by research institutions to support the professional development of their employees to comfortably and appropriately engage members of the community with lived experience or who come from diverse backgrounds outside research. Providing this training and ensuring that researchers are equipped to undertake meaningful and informed engagement ensures that community members are safe and also builds self-efficacy in researchers which creates attraction in engaging in areas of research that may have been previously avoided due to limited capacity and understanding.

- Does the Statement clearly explain the roles and responsibilities of **Research Funders** that ensure effective consumer and community involvement?

Yes ☒
No ☐

Would you like to make further comments?

The Alliance agrees in principle with outlined roles and responsibilities of Research Funders. Under the subsection "Making funding decisions", the Alliance sees the potential for the addition that research funders agree to provide funding in accordance with the involvement expectation they set and that funding is appropriate to the project, community and research capacity. This addition would ensure that funding is reflective of higher costs associated with undertaking research in rural and remote areas and ensures that the financial contribution meets the output expectation, mitigating chances of burnout in researchers and community and consumer participants in rural areas who may be operating in areas of limited workforce, resources and support. Research in rural Australia is no less valuable, nor less important, than that which is carried out in metropolitan communities. This imbalance of funding allocation and support must be addressed, whether by mentoring, capacity building or funding.

Implementing the Statement

The Statement is intended to be a high-level, overarching document that does not focus on issues related to implementation of consumer and community involvement in health and medical research. It instead creates a strong expectation of consumer and community involvement in all health and medical research and provides high-level guidance.

Implementation is the process of putting recommendations into practice. Supporting the effective implementation of consumer and community involvement may include things such as providing additional support or resources.

Responses to the questions below may be used to develop implementation guidance once the revised Statement is published.

- What else is needed to support the effective implementation of consumer and community involvement?

The Alliance believes that prioritising research projects and proposals that provide clear and well-planned population health need consumer involvement and capacity building, particularly those proposals that engage with priority populations including rural and remote communities would support the implementation of consumer and community involvement.

This inclusion would ensure that high standards of consumer and community involvement are rewarded, setting broader expectations and industry standards for community and consumer engagement within the research community. In turn, this would also result in better health outcomes for priority populations who have poorer health outcomes, earlier deaths, low healthcare access and are not well represented within the research space.

The Alliance also envisions that creating strong communities of practice within the research will be an important aspect to implementing the Statement. Supporting the creation of communities of practice will allow for researchers and community research partners to share their successes and challenges in consumer and community partnership research projects. This information sharing will lead to the strengthening of future proposals, and the opportunity to disseminate research outcomes more broadly and provide networks for other community and consumer research partners to connect and support each other in their roles. These communities of practice are particularly important for rural and remote communities where researchers may be operating in isolation and could be supported or mentored by their peers in other centres.

In the National Rural Health Alliance's Pre-Budget Submission 2025-26, the Alliance has proposed that the Federal government commit to rural health capacity and capability building investment through the specific funding of a Rural Health Innovation and Evidence Hub, hosted by the Alliance. The Hub would support real-time learning from rural health systems and communities' innovation across Australia through regular forums in rural communities and a strengthened Australian Journal of Rural Health, supported by an IT platform with artificial intelligence integration. Innovation, research and grass roots led solutions occurs across rural Australia currently, however, there is no one place or community of practice where an entity, a clinician, a researcher, community or local government can go to learn, adapt or adopt what is learnt or being done somewhere else in rural Australia. This is a great loss of ideas and action.

While this is not within the scope of the current consultation, the Alliance recognises synergy between facilitating communities of practice, research and synthesis through this platform and the proposed Statement on Consumer and Community Involvement in research.

Additional Comments

- Do you have any additional comments on the Statement?

The Alliance wishes to commend the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia (CHF) for the production of a high-quality, inclusive Statement on Consumer and Community Involvement in Health and Medical Research. The Draft Statement is comprehensive and provides a concise outline of expected roles, responsibilities and values associated with undertaking community and consumer involved research.

The Alliance believes that, with a strong implementation plan and an adjustment of language, the Statement will have significant positive impacts on the rural health research sector. Rural healthcare is a complex and unique landscape. Healthcare needs and solutions vary greatly between communities. Consumer and community involvement in health and medical research are fundamental to creating health equity for rural and remote Australians who, despite representing approximately one-third of Australia's population, have lower life expectancy and poorer health outcomes compared to their urban counterparts.

Due to the complex geographic, funding, policy, socioeconomic and healthcare needs of rural Australians, researchers must be committed to engaging in both trauma-informed and culturally aware research to support community and consumer research partnerships. Researchers and research organisations have a social and ethical responsibility to invest in ongoing relationship building activities to ensure that community and consumer involved research goes beyond merely fulfilling a funding requirement and translates into tangible healthcare outcomes for rural communities. This must also come in the form of shared ownership of research outcomes and self-determination of data.

To adequately fulfil these requirements, the National Rural Health Alliance emphasises that there must also be equity (not equality) and parity in relation to funding. This means that research funders must be cognisant of long term under funding of rural Australia, and higher costs related to providing services and research in rural and remote areas. As Australian taxpayers we must commit to adequately supporting rural consumer and community involved research by providing appropriate funding. This includes allowing for appropriate funding to source any social or psychological support needed to coach and provide supervision for community members participating in research that may be distressing.

It is important that research that focuses on rural Australia is prioritised by researchers, educational institutions, and funding bodies. The Alliance, and the communities it represents consistently see that research outcomes that are translated into policy directives often are unable to be implemented in a rural context. For this reason, it is imperative that communities are involved in orientating rural health and medical research as they are able to provide key insights for researchers into the unique and complex healthcare experiences of rural Australians.